Palliative care for Muslims and issues before death

AR Gatrad, A Sheikh

Abstract

National and European directives have now enshrined within European law the requirement that health-care professionals provide their patients with culturally appropriate and sensitive care. Although well intentioned, many health professionals find it difficult to translate these directives into practice. Barriers to providing culturally competent care include racism, institutional discrimination and gaps in our understanding of the interface between culture and health - this latter factor reflecting the lack of training in transcultural health care. In this paper, we concentrate on issues relating to the provision of palliative care near death to Muslims of South Asian origin in the UK, although much of what is said will equally be applicable to Muslims from other parts of the world. This is the first of two articles giving insights into the palliative care of Muslims. The second article 'Palliative care of Muslims and issues after death' will appear in a later issue.

'Civilisation is judged by the treatment of it's minorities'
(*Mahatma Ghandi*)

Muslims follow the religion of Islam which traces its origins to the same Semitic soil that bore Judaism and Christianity. Its most profound tenet is a belief in monotheism, summarized in the Declaration of Faith:

'There is no deity save God, and Muhammad is the Messenger of God.'

This is whispered almost universally by Muslims into the ear of their newborn or a dying loved one. The daily life and body of Muslim communities pivot around this statement. Life's very purpose then is to realise the Divine, an aspiration that is achievable only through a conscious commitment to the teachings of Sacred Law.

In this, the first of two papers, we discuss issues concerning breaking bad news and customs when death is close for practising Muslims of South Asian origin, i.e. those from India, Pakistan or Bangladesh. Implicit in our approach is a recognition that factors other than religion, such as culture, are also important in shaping the practices of Muslim minority communities in the UK.

As practising Muslims, we explore the concept of palliative care for Muslims, taking an 'insider's perspective'. Through sharing our multidisciplinary understanding and experiences, we hope to stimulate discussion and debate regarding possible strategies to raise awareness of Muslim culture. Our aim is to facilitate a change in practice that will bring about care that is truly patient centred.

Culture and health

Palliative care has historically focussed on cancer, which makes up 95% of the total use of palliative services (Tebbit, 2000). In their book, *Opening Doors*, Hill and Penso (1995) highlighted that ethnic minorities in general were not using hospice and palliative care service in proportion to their numbers. This study, however, did not address the perspective of the service users and hence did not address the differences between different cultural groups. In her book, *Wider Horizons*, published some years later, Firth (2001) acknowledged that the service was still not commensurate with the ethnic minority population partly because the provision of care was based on western models. A study of Muslim Pakistanis (Cortis, 2000) confirmed that racism and intolerance was still rife. This led to a resigned acceptance by the patients of the way they were treated.

When discussing culture, it is important to recognise that culture is a dynamic entity. Migration often accelerates the process of change, typically through the phenomenon of acculturation, that is, the process by which minority cultures take on the features of the majority.

The metaphor below is commonly used by anthropologists and sociologists seeking to explain the role of culture in shaping outlooks:

'The inherited lens through which we see, experience and interact with the world'

The role of culture is particularly important in determining notions of illness, disease, health and healing among Muslim communities.

AR Gatrad is Consultant Paediatrician, Manor Hospital, Senior Lecturer (Honorary), Birmingham University, Honorary Assistant Professor (Paediatrics) University of Kentucky and **A Sheikh** is National Primary Care Training Fellow, Department of Primary Care and General Practice, Imperial College of Science, Technology and Medicine, Chairman, Research and Documentation Committee, Muslim Council of Britain

In Walsall in the West Midlands (UK), 450 adult Muslims were surveyed after Friday prayers (AR Gatrad, unpublished observations, 2001) by the authors at three mosques in a predominantly Muslim area. Most of those surveyed (410) attended the surgeries of three well-established Asian GPs. These doctors had graduated in India, two were Muslims and one was Hindu. When asked about palliative care for Asian patients they all thought that the family would prefer to look after them. On the other hand, when three British Muslims who had graduated in the UK were asked the same question, they felt that, as circumstances were changing with the breakdown of extended families, hospice care should be explored more than previously. We therefore should not assume that 'they will look after their own'.

Approximately one-third (over 600 000) of Britain's estimated two million Muslims trace their origins to the Indian subcontinent, that is, India, Pakistan and Bangladesh, sometimes referred to as South Asian countries. Sizeable numbers come also from Europe (Albania, Bosnia, Cyprus and Turkey), Arabia (Iran, Iraq and the Arabian Gulf), and parts of northern and central Africa (Anwar, 2000). As our appreciation of the relationship between religion, health and healthcare increases, it is becoming increasingly apparent that the 'end-of-life' issues represent a period when understanding and sensitivity is particularly important (*Table 1*).

Table 1. Case study: a mother's remarks after her daughter died of leukaemia

Doctors were too busy and nurses were vague
No one was telling us directly what was happening
They were talking jargon
Nursing staff was rude and insensitive in repeatedly sending us home. I only wanted to be with my daughter as much as possible before she died

Table 2. The stages of life

Life before conception
This stage refers mainly to a pledge made by each soul, before entering this world, to worship none other than God. The innate ability to perceive truth is considered a manifestation of this original divine encounter

The Lower World
Life on earth

The intermediate realm
From the time one departs from earth to the Judgement Day

The Garden and Fire
The eternal abodes

Death: the Muslim context

For most people death is the last great taboo. The thought of taking our final breath is something we consciously ignore and for many of us it is nothing short of morbid. Not withstanding this, death rituals for Muslims form the final bond between the deceased and the bereaved. As Muslims believe in the afterlife and the Day of Judgement they regard death as a transition from one phase of existence to the next, as shown in *Table 2*.

Islam teaches that life on earth is an examination, the fruits of which will be reaped in the afterlife. Death is therefore accepted as part of a divine plan and is not a taboo subject. Muslims are often encouraged to talk about death and reflect on their own existence in its context.

The difference between not suggesting further treatment in a hospital and improving the quality of life in a hospice, i.e. focus shifting from cure to care is not very clear in the Muslim 'psyche'.

Types of patient requiring palliative care

The most common reasons for Muslim children to require palliative care are neuromuscular disorders, rare metabolic and genetic disorders and, to a lesser extent, cancers such as leukaemia (personal communication, Erica Brown Acorns Hospice, Birmingham, UK, 2002). The most common reasons for adult Muslims to require palliative care are the presence of cardiovascular disease and the complications of diabetes, rather than the presence of cancer. Mortality from these two conditions in those over 65 years has been found to be 55% higher in people from Pakistan and Bangladesh than those born in England and Wales (Balarajan and Raleigh, 1995). We may have to re-examine policies and systems if we are to meet demand over the next decade. Not only will there be a large population of Asians over 65 years, but the need for palliative care services is likely to be increased by breakdown of the extended family structure.'

Care of the dying

Extended and nuclear families

An extended family structure is typical of Muslim families. It is important to realise that family dynamics in these cultures are very different from those customary among people from the west. For example, the family is more frequently extended (although this is changing), hierarchical and patriarchal, with males and females

'...with more and more young Muslims becoming professionals and moving away from their family homes, this [unconditional loyalty to elders in the family] is slowly eroding. The breakdown of family structure is likely to lead to more demand for palliative services.'

operating in different, yet complimentary, ways. The male may thus be seen as the primary breadwinner with overall control (and responsibility) for managing family finances, while females may take a lead role in bringing up children and the day-to-day upkeep of the family home. These generalisations should not, however, lead to stereotyping. Among Muslims, such role demarcation is seldom seen as sexist or discriminatory but rather as reflects the complimentary and synergistic nature of male–female relationships. Palliative care, which may start from the time of the breaking of bad news, should therefore be delivered in a way which acknowledges these factors.

Filial piety, described by Boyle (1998), is still very much present in the Muslim culture. This implies unconditional loyalty, respect, love and honour for the elders in the family. However, with more and more young Muslims becoming professionals and moving away from their family homes, this is slowly eroding. The breakdown of family structure is likely to lead to more demand for palliative services. In addition to understanding the diversity of cultures, the NHS will have to put in place strategies to meet translational difficulties. These may become more common with the loss of English-speaking children from family homes. Introducing care-giving interventions that are sensitive to cultural norms is becoming more important because the average age of Asians in the UK is increasing. Pearce and White (1994) found that, among people of pensionable age, long-term illness was reported to be higher in Indian and Pakistani households than in those of Caucasians.

For Muslims, care of the dying, a regular and essential responsibility of extended family life, has, historically at least, been managed at home. There exist numerous traditions of the Prophet Muhammad extolling the virtues of caring for the ill and particularly those in the last days of their life on earth. The aim of such 'care' is to encourage and support the dying and to cement firmly their relationship with God and kin before the imminent meeting with God on Judgement Day. The final illness thus represents a crucial period when people will wish to be surrounded by family and close friends who can take on the challenging task of fostering metaphysical 'growth' at this most vulnerable time. Palliative care of Muslims therefore involves not only the immediate and extended family but also the Muslim community at large. Many may see being nursed by strangers in an alien secular environment as an anathema. It is therefore not surprising that there exist very few hospices in the Muslim world; indeed, the terms 'hospice' and 'to palliate' have no direct equivalent in many Asian languages.

It is of interest to note that Islam has specific rules and regulations regarding a person's 'last will and testament'. In Islamic law all children should receive a proportion of the estate of the deceased and the wife or husband have to be included as beneficiaries.

Disclosure

Our experience suggests that many families do not wish their dying relative to be informed of the prognosis. This should be given to the immediate relative who may or may not wish for a disclosure to the patient. This is in keeping with Firth's observation (2001) that various ethnic minority groups, including Muslims, prefer non-disclosure as there is a high chance of 'loss of hope'.

However, our experience also suggests that most, even the young, are usually aware that they are dying, at times as a result of cues picked up from parents and staff. Patients and relatives may also maintain a 'mutual pretence' (Bluebond-Langner, 1978). The reluctance of relatives and health professionals to talk about issues of death and dying affects the way a family copes with grief. We suggest that an honest yet sensitive approach is adopted when discussing issues to do with prognosis. Note, however, that optimism and hope are regarded as some of the fruits of Faith in Islam.

The main languages spoken by South Asian Muslims are Urdu, Gujarati and Silethi. However, most will have some understanding of Hindi. The provision of adequately trained interpreters is of paramount importance. A study by Spruyt (1999) showed that when Bangladeshi children were involved in interpretation during the care of a dying relative, this had a negative impact on their school attendance, some gave up school and other older sons gave up work to look after their ill relative.

Relatives of the ill, particularly if young, may be reluctant to talk about the illness

to others, if the illness is genetic, as it may affect the marriage chances of other members of that family.

Home, hospice or hospital?

In general, research has shown that when children die at home, long-term outcome is better for parents (Lauer et al, 1989). Making death clinical and having it occur in a hospital setting are not in keeping with Islamic tradition. The dying will expect to be visited by friends and relatives who are encouraged to pray for their welfare in the life to come. It is considered a Sunnah (a practice of Prophet Muhammad) to visit the sick. This is a time when Muslims seek each other's forgiveness for excesses that may have been knowingly or inadvertently committed in the past. Members of the immediate family will often stay by the bedside reciting from the Qur'an hoping to imbue peace and serenity into the heart of the loved one.

Saying prayers at home may help alleviate 'spiritual pain' better than saying prayers in institutional settings, which are often considered alien. In the Indian subcontinent dying patients often return home to die. Although there is a dearth of research into the preferred place of death, a study by Gardener (1998) confirmed that among Muslim Bangladeshis, home was a sacred place to die. Some may wish to travel abroad during their last illness. This is generally for one of two reasons. First, relatives may want traditional healers (Hakims and Pirs) to be consulted to see if they can effect a cure. Second, there may be a desire for death to occur in a sacred location such as the 'Blessed city' or the 'Enlightened city of the Prophet', better known as the Saudi Arabian cities of Mecca and Medina respectively. Should travel be anticipated for such purposes, it is important that the prognosis is discussed realistically as the opportunity for travel may slip away. Although Muslim undertakers in East London estimate that 60–70% of Bangladeshi corpses are repatriated (Firth, 2001), in our experience it is adults rather than children that are sent abroad for burial.

Table 3. Examples of good practice before death

Creating confidence and a close relationship, not only with the patient, but also with the main family carer/carers. This is particularly important if the family are relying on care at home
Learning and understanding some words in the language of the family – this is much appreciated by the families and helps create a bond. A simple Muslim greeting of Assalamu Alaikum goes a long way in breaking barriers and creating trust
Providing 'space' for relatives to visit in numbers and pray if necessary
Provision of Prayer artefacts in the form of mats, beads, incense sticks and a special compass for the direction of prayer towards Mecca. Some hospices, such as the Acorns in Birmingham, provide the direction on the window in the form of an arrow
Discussing dietary needs – whether food can be brought from home. Rigid laws regarding food being brought into hospices/hospitals may need reviewing in the light of special circumstances of death where a patient may not eat hospital food believing it not to be halal at a time when he is so close to meeting his Lord
After using the toilet Muslims usually use water for cleansing. Thus a jug or a plastic bottle kept within the confines of the toilet would help this practice
All religious books, such as the Qur'an, should be treated with the utmost respect by being kept on a separate shelf and only handled when covered with a clean piece of cloth/scarf
Appropriate audio tapes of the Qur'an should be made available for use if necessary. Advice from the Muslim 'Chaplain' attached to the hospital should be sought in setting up appropriate palliative services
Nurses of the same sex as the patient should be involved with care which requires exposure of intimate areas

Prayers and spirituality

For Muslims, the spiritual dimension of death is paramount, since death marks the separation of the real and the surreal, the sacred and the profane. Spirituality for Muslims is concerned with the transcendental, inspirational and existential way of being in relationship with God. This spirituality is heightened as the individual confronts death (Dom, 1999). Thus the provision of adequate space for performing prayers and of prayer artefacts, as mentioned in *Table 3*, would be greatly appreciated by the family and indeed the community.

Muslims are expected to pray five times daily from the age of 10 years. These prayers have a pivotal role in the lives of Muslims and assume an even greater role in times of distress for the family. Before any prayer, ablution is performed – bedbound patients will need help in this regard. There is a physical element to the daily prayers. If debilitated, the patient can perform prayers in bed by simulating the actions or by 'praying in the mind'. Muslims pray facing Mecca. A specially designed compass is available from mosques and Muslim bookshops to accurately define the direction. Many visitors will also often perform their prayers during visits to the hospital. Ablution facili-

ties for the relatives and also the provision of a jug/plastic bottle in the confines of the toilet would be greatly appreciated by Muslim families. After any toileting Muslims cleanse themselves with water (*Table 3*).

Practical aspects of care

Islam views life as a 'sacred trust' from God. Thus suicide and deliberate euthanasia are categorically forbidden (Sheikh, 1998). As expressed in the Qur'an:

> **'Whosoever takes a human life – it is as if he has taken the life of whole mankind.'**
> (*Qur'an 5:32*)

Conversely, undue suffering has no place in Islam and if death is hastened in the process of giving adequate analgesia then there is no objection. Prolongation of life by artificial means is disapproved by Islam unless there is evidence that a reasonable quality of life would ensue (Rahman, 1987).

A black string (Tawiz) with a pouch containing religious scriptures may be tied to the wrist or around the neck of the patient. During practical procedures on the patient this should not be disturbed without the consent of the patient or relative.

The limited empirical evidence available suggests that perceptions and expressions of pain are strongly shaped by culture. The exact location and meaning of pain has to be ascertained accurately as a patient may say that his 'heart is burning' or 'hurting' and mean that he is upset. A project currently being undertaken into pain experiences of ethnic minorities by the University of Birmingham (UK) should help improve our understanding of issues around pain (Pitches, 2000). It is important to notify relatives that if opioids are used to control pain, this may have a negative impact on cognitive ability and levels of consciousness. It will be hoped by relatives that the final utterance of the dying will be a reaffirmation of their declaration of Faith (*Table 4*). The presence of non-Muslim health professionals who are unaware of this rite of passage may inhibit the relatives from performing it.

During the 'last moments' Muslim communities will encourage the dying to recite the Shahadah (*Table 4*) in Arabic and may encourage the drinking of Holy water (Zam Zam), a process called 'Sakrat'. Zam Zam, obtained from the wells of Mecca in Saudi Arabia, may be given as a drink to the dying patient or be applied to various parts of the body. Relatives usually bring it in. Each family member present may attempt to give a sip of water to the dying. Nurses should always ensure that this water is not thrown away inadvertently.

It is believed that the fate of Muslims is sealed from the time of birth. This may be the reason why some patients are reluctant to undergo treatment, believing that to do so would be to defy God's will (Boyle, 1998).

Withdrawing treatment

Withdrawing treatment from any patient is difficult. However, it is easier for Muslim doctors, such as ourselves, who share a common heritage and a world view, to withdraw treatment from Muslim patients than for non-Muslim doctors. In such circumstances, after making it clear to the relatives that the patient's interests are our foremost concern, it is often possible to make use of Islamic teachings in counselling relatives regarding the difficult decisions ahead. We remind relatives of the transient nature of our earthly sojourn in contrast to the abiding reality of the afterlife. The exact time of death is a matter of Divine decree over which we as fellow human beings are only bystanders. In these situations we show guarded confidence in our ability to deal with the medical and spiritual aspects of the terminal phase and discuss the possibilities of how the illness will take its course. In the care of children we remind parents that children are born pure according to the teachings of Islam and those (relatives) who remain true to their religion and abide by the teachings of Sacred Law will join their children in paradise.

Most Muslim authorities will consider brainstem death as an acceptable sign of death. A minority, however, are of the opinion that the concept of brainstem death is not acceptable in Islam and therefore argue that death is the point at which the soul departs.

Table 4. The Shahadah

The Prophet Muhammad (may God's peace and blessings be with him) taught:

'Encourage your dying ones to say the affirmation of Faith. Whosoever's final words are the Shahadah, "There is no deity but God; Muhammad is the Emissary of God" will enter the Garden.'

KEY WORDS

- Muslim
- Palliative care
- Ethnic minority
- Death rites
- Pre-death rites

Conclusion

Respect for the religion and culture of all faiths is important if health professionals are to deliver care that is truly patient-centred. For practising Muslims the experience of death and dying represents a key time in the faith of the patient, their family and the community. In addition to offering understanding and respect, there are a number of practical measures that healthcare professionals can take to help Muslims at this time.

Changes in the culture of South Asian Muslims, such as the breakdown in the extended family, are likely to lead to an increased use of palliative care services. There is therefore an increasing need for culturally sensitive services. We hope that our explanations of Muslim faith and culture, both here and in the next article, will serve as a small step towards improved understanding between different cultures.

Anwar M (2000) Muslims in Britain: demographic and socio-economic position. In: Sheikh A, Gatrad AR, eds. *Caring for Muslim Patients*. Radcliffe, Oxford: 4–7

Balarajan R, Raleigh VS (1995) *Ethnicity and health in England*. NHS Ethnic Unit. HMSO, London

Bluebond-Langner M (1978) Mutual pretence: cause and consequence. In: *The Private Worlds of Dying Children*. Princeton University Press, Princeton, NJ: 210–30

Boyle DM (1998) The cultural context of dying from cancer. *Int J Pall Nurs* **4**(2): 70–83

Cortis JD (2000) Perceptions and experiences with nursing care: a study of Pakistani (Urdu) communities in the UK. *J Transcult Nurs* **11**(2): 111–18

Dom H (1999) Spiritual care, need and pain, recognition and response. *Eur J Palliat Care* **6**(3): 87–90

Firth S (2001) *Wider Horizons*. National Council for Hospice and Specialist Palliative Care Services, London

Gardener K (1998) Death, burial and bereavement amongst Bengali Muslims. *J Ethn Migr Stud* **24**(3): 507–21

Lauer ME, Mulhern RK, Schell MJ, Camitta BM (1989) Long term follow up of parental adjustment following a child's death at home or hospital. *Cancer* **63**: 988–94

Pearce D, White I (1994) 1991 census of Great Britain: Summary. *Popul Trends* **78**: 34–43

Pitches D (2000) *Health services in Birmingham for Black and minority ethnic older people: Report of a baseline survey for Birmingham*. Race Action Partnership. Birmingham Health Authority, Birmingham

Rahman F (1987) *Health and medicine in the Islamic tradition*. Crossroad, New York: 108–9

Sheikh A (1998) Death and dying – a Muslim perspective. *J Roy Soc Med* **91**: 138–40

Spruyt O (1999) Community based palliative care for Bangladeshi patients in east London: Accounts of bereaved carers. *Palliat Med* **13**: 119–29

Tebbit P (2000) *Palliative care 2000 Commissioning through partnership*. National Council for Hospice and Specialist Palliative Care Services, London

TO BE SURE TO GET YOUR COPY

CALL 0800 137 201 NOW

Volume 8 Number 10
October 2002
International Journal of Palliative Nursing
Promoting excellence in palliative care

International Journal of Palliative Nursing

The only monthly peer-reviewed journal promoting excellence in palliative and supportive care

Copyright of International Journal of Palliative Nursing is the property of Mark Allen Publishing Ltd and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.

Copyright of International Journal of Palliative Nursing is the property of Mark Allen Publishing Ltd and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.